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THE MEASUREMENTS OF RARE CANCERS

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Introduction

The N. Ireland Cancer Registry founded in 1994 provides information on cancers and pre-malignant disease occurring in Northern Ireland for research, education, service monitoring and planning. It collects morphology codes using international classifications and has data on pathologically diagnosed rare tumours which arise in non-rare anatomical sites. E.g. Anaplastic carcinoma of the thyroid.

NICR Methods of working

N. Ireland Cancer Registry – Multiple sources of data



The registry provides a secure confidential environment for the storage and analysis of the sensitive clinical data having received ISO 27001 accreditation. It has links with the NI biobank facilitating the collection of clinical details on biological samples



Statistics

From 2011 to 2015, on average, there were 4,557 male and 4,516 female patients diagnosed with cancer each year excluding Non-Melanoma Skin Cancer (NMSC). There were an additional 2,065 male and 1,576 female patients diagnosed with NMSC. Included in this total are many rare cancers usually categorised as 'other' amounting to approximately 1200 cases per year, some examples of these, their codes and number of cases is below. See www.qub.ac.uk/nicr for details of outputs from the registry.

Site	ICD 10 code	Morphology	Average number per year*
Hepatocellular carcinoma of liver and intrahepatic bile tract (IBT)	C22	8170-8175, 8180	172
Chronic myeloid leukaemia	C92.1, C92.2	9863, 9875	15
Mixed epithelial and mesenchymal tumours of the uterus	C53.0-C55.9	8933, 8950-8951, 8980	13
Epithelial tumours of nasal cavity and sinuses	C30.0-C31	8000, 8001, 8004, 8010, 8011, 8020-8022, 8032, 8050-8076, 80878, 8082-8084, 8123, 8144, 8560, 8980	8
Gastrointestinal stromal sarcoma	Any	8936	5
Malignant melanoma of uvea	C69.3-C69.4	8720-8780	3
Kaposi's sarcoma	Any	9140	2
Malignant meningiomas	C70	9530, 9538-9539	1

Work is ongoing at European and international level to standardise recording and categorisation of these rare tumours and to combine datasets from many countries to enable epidemiological and scientific study including Joint Action on Rare cancers work package 4 - Improving epidemiological surveillance on rare cancers in Europe.

